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ABSTRACT

This paper looks at independent housing needs of persons with disabilities and presents a policy statement developed by the Center on Human Policy in December, 1989. Noted are the results of a research review showing that housing needs are similar for all disability groups, that supports are a critical factor in housing provision, that housing problems are less related to disability than to economic and social factors, that differences exist between professionals and people with disabilities regarding perceptions of specific housing and support needs, and that choices and control are critical elements. Encompassed within the institute statement are three major themes: (1) the importance of living in one's own home; (2) the context of the broader community in people's lives; and (3) the extension of the independent living movement's concept of personal assistance to people with severe developmental disabilities. A chart compares the rehabilitation, independent living, and support paradigms for such dimensions as problem definition, social role/s, control, and desired outcomes. (23 references) (DB)

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LIFE IN THE COMMUNITY: "A HOME OF MY OWN WITH THE SUPPORTS I NEED OR WANT"

by
Julie Ann Racino
Center on Human Policy

August 1991

During the past six years, the Center on Human Policy has studied a growing number of places throughout the United States where adults with disabilities, who were previously confined to life in facilities, are living in their own homes with support services. When we first began our search for exemplary practices in 1985, we expected to identify many good examples of group homes and apartment living, which were considered at the time to be "progressive options." Instead, we found practices that represented a new way of thinking about life in the community for people with severe developmental disabilities, practices that seemed to be influenced by the philosophy of the independent living movement.

Emerging across the United States today are new options for adults, whether single or married, to live in their own homes, no matter what their ability level. Termed "supported housing" in the field of mental health (Carling, in press), "person centered," "nonfacility-based," "individualized," or "housing and support" in the field of mental retardation and developmental disabilities (e.g., O'Brien & Lyle, 1986; Racino, 1989; Taylor, Racino, Knoll, & Lutfiyya, 1987) and "assisted living" in the field of head injury (NYS Head Injury Association, 1990), these efforts build on the basic premises of the independent living movement. Unlike the traditional professional approach of establishing residential programs and fitting people into the program, these efforts are based on the premise that everyone has a right to live in a home and have the support services necessary to do so. In the independent living movement, many of these support services would be called personal assistance services, if the term was broadly defined to include a range of different activities.

Shared Issues in Housing and Support Services

In the ensuing years, as we looked at these issues across different groups of people in the community, we found that many different groups are now facing common problems in community life. For example, a comprehensive review of research related to housing and community integration for all disability groups (Carling, Randolph, Blanch, & Ridgeway, 1987) concluded that:

(1) Housing needs are similar for all of these groups;

(2) Supports are a critical factor which determines if a person can stay in housing of their choice;

(3) Housing problems are less closely related to disability than they are to economic and social factors., such as poverty;

(4) Regardless of disability groups involved, strong differences exist between professionals and people with disabilities about specific needs for housing and support;

(5) Choices and control are critical elements.

Thus, we found that housing and support services (which includes personal assistance services) issues must be examined across different groups, if we are to effect the systemic changes that will give all people the choice to live at home in the community. This choice is denied many people today, including over 90,000 people with developmental disabilities who were still residing in state institutions across the United States in 1988 (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1989).

Organizing to Challenge Service Systems

Within this context, in 1989, we hosted a two day national policy institute to develop a statement in support of adults in living in the community. Encompassed within this statement (See Figure 1) are three major themes: the importance of living in one's own home; the context of the broader community in people's lives; and the extension of the independent living movement's concept of personal assistance to people with severe developmental disabilities. In the words of Gunnar Dybwad, an international leader in the field of mental retardation, "Any of these concepts fully applied will challenge the service system as it today exists."

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FIGURE 1
IN SUPPORT OF ADULTS LIVING
IN THE COMMUNITY

ADULTS, REGARDLESS OF ABILITY, SHOULD HAVE THE RIGHT AND OPPORTUNITY TO LIVE IN A HOME OF THEIR OWN IN THE COMMUNITY.

Adults should have the right and opportunity to live in typical, decent, safe, accessible, and integrated community housing.

Adults, whether married or single, should have choices about the neighborhood they live in, the style of community housing, and the people with whom they will live.

Adults should have the same tenant and ownership rights and opportunities as other citizens, including the option to own or lease their own homes or apartments.

Adults should have the opportunity to live in housing free from the conflicting relationship of landlord and service provider.

Adults should have the opportunity to create a home of their own, reflective of their personal routines, values and lifestyles.

ALL INDIVIDUALS SHOULD BE ENTITLED TO THE SUPPORTS AND PERSONAL ASSISTANCE NEEDED TO LIVE IN THEIR OWN HOME AND PARTICIPATE FULLY IN COMMUNITY LIFE.

Adults should receive whatever personal assistance and supports they need to live fully in their own home and community with dignity, self-determination and respect.

Adults should have the option to live in their own homes in the community without risking the loss of material or personal assistance support.

Adults shall have maximum control over their personal assistance and other supports, with advocacy and support, independent of service agencies, in making these decisions.

Adults have a right to determine who will provide personal assistance and supports.

ALL ADULTS SHOULD HAVE OPPORTUNITIES TO PARTICIPATE IN COMMUNITY LIFE

Adults with disabilities should have opportunities to be involved with ordinary people on a partnership basis and to develop relationships with neighbors, co-workers and community members.

Adults with disabilities are entitled to decent, safe, and affordable housing; financial security to meet basic needs; health and medical care; and community transportation, employment and recreation.

Adults should have opportunities to contribute to the diversity and strength of communities.

Center on Human Policy
December 1989

All people, regardless of severity of disability, can live in their own homes in the community. People should have choice about where and with whom they live, control over their environment and how they spend their time.

Gail Jacob
Options in Community Living
Madison, Wisconsin

While in the 1980s, the goal was a "home-like environment," the next decade should challenge us to examine the essence of what it means to live in one's own home. A small, but important part of this movement should be the extension of home ownership strategies to people with disabilities, without the threat of loss of support services. Wherever people choose to live, support services should be available.

Increasingly, home ownership and rental are becoming options for people with disabilities who previously were limited to life in agency facilities (see, for example, FY 1991, Administration on Developmental Disabilities Priorities). Strategies such as the development of cooperatives, the use of trusts for typical housing, and the purchase of homes through housing associations are being pursued to assure that people, including those with disabilities, will have access to affordable, accessible places of their own (e.g., Kappel & Wetherow, 1986; O'Connor & Racino, 1990; Randolph, Carling, & Laux, 1987).

People can live wherever they want to live if they have adequate support services.

Judy Heumann
World Institute on Disability
Oakland, California

The concept of personal assistance services offers some promise in thinking about how to support people with severe developmental disabilities to live in their own homes. While a primary agenda issue of the independent living movement (Litvak, Zukas, & Heumann, 1987), the inclusion and meaning of such services in the lives of people with mental retardation and developmental disabilities (e.g., Connecticut Developmental Disabilities Legislative Platform, 1988; Nosek, 1990) is just starting to attract the attention and discussion it requires.

More thoughtful analysis of personal assistance issues, including perspectives of people with developmental disabilities (in contrast to the perspectives of representatives), the relationship and role of allies and supporters, and complexities in choices and decision making, is beginning to be pursued (e.g., Centre for Research and Education in Human Services, 1989; Traustadottir, 1990). To move forward on these issues, greater exchange is necessary between different groups to better understand the language that often divides us into smaller interest groups and to combat our own prejudices that at times, allow us to settle for less than we would accept, for people with severe developmental disabilities.

The aspect of choice which is so strongly incorporated in the concept of personal assistance services is still only a small part of the concept of support services in the developmental disabilities field. While there are some examples of people with developmental disabilities hiring, firing and managing their own attendants with the support of an agency (e.g., Johnson, 1985), many of the new efforts still maintain control in the hands of agencies. While people with disabilities are involved in more individualized ways and have more choices, the fundamental control, particularly in situations of values conflicts, has not yet shifted into the hands of people with disabilities. We all must address our attention to these critical issues.

This statement should include a comment to community leaders...about inclusiveness and celebrating gifts and capacities of people with disabilities as community members.

John Winnenberg
previously of Residential, Inc., Ohio

Instead of people simply being physically present in the community, there is increasing recognition of the importance of being part of the community. While service systems can play some roles, the importance of relationships, the interactions between informal supports and formal services, the roles of ordinary citizens, and the contributions by people with disabilities are coming to the forefront.

While both the independent living movement and the support paradigms (e.g., Crewe & Zola, 1983; Racino, 1991; Smull & Bellamy, 1990) stress the need for support

FIGURE 2: A COMPARISON OF THE REHABILITATION, INDEPENDENT LIVING AND SUPPORT PARADIGMS

Focus	Rehabilitation Paradigm	Independent Living Paradigm	Support Paradigm
Definition of problem	Physical impairment; lack of vocational skill; psychological maladjustment; lack of motivation and cooperation	Dependence on professionals, relatives, and others; inadequate support services; architectural barriers; economic barriers	Attitudinal, political, economic and administrative barriers to societal participation; inadequate supports within society
Locus of problem	In individual	In environment; in the rehabilitation process	In society/environment; in rehabilitation process
Social role(s)	Patient-client	Consumer	Co-worker, community member, student, neighbor, etc.
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, vocational counselor, and other	Peer counseling; advocacy; self-help; consumer control; removal of barriers and disincentives	Redesign of schools, homes, work places, health care systems, transportation and social environments to include all
Who controls	Professional	Consumer	People in alliance with each other
Desired outcomes	Maximum ADL; gainful employment; psychological adjustment; improved motivation; completed treatment	Self-direction; least restrictive environment; social and economic productivity	Pluralistic society inclusive of all people; quality lives as defined by people themselves; self-direction embedded in collaborative decision making and problem solving

DeJong, 1978 and 1983 (in Lachat, 1988) Racino, 19[illegible]1

services, services can often hurt as well as help and can create further barriers to integration and participation. There is a need to look beyond the role of services to the commonplace everyday roles and interactions in home and community life.

Future Directions in Housing and Support

To develop a common base for future directions, Figure 2 compares the rehabilitation, independent living and emerging support paradigms in the fields of mental retardation and mental health. As with the independent living paradigm, the support paradigm will demand changes on the part of all of us, including individuals, families, agencies (community and disability), systems, neighborhoods, communities, and societies.

While the reader is referred to other texts for further analyses (e.g., Racino, Walker, O'Connor, & Taylor, in press), the Figure 2 is an attempt to seek common ground between different movements and to create discussion that can result in a common vision to guide future efforts toward societies inclusive of all. Personal assistance services is one of many avenues through which this discussion and collaboration can begin.

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